



Waiver Wise

Technical Assistance for the Community Options Program Waiver COP-W

Wisconsin Department of Health & Family Services • Division of Supportive Living
Bureau of Aging & Long Term Care Resources

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Incorporating the Participant Voice In County Programs

The Value of Participant Voice

In growing numbers human and social service agencies are tapping into the expertise of participants on long term care programs. These agencies have long recognized the benefits of participant input, but they are now diversifying and formalizing their approaches to incorporating the participant voice. As a result, participants and long term support agencies are benefiting from this effort.

By giving people a voice in their everyday lives and encouraging them to shape long term care policy in Wisconsin, the Community Options Program (COP) and the COP Waiver/CIP II programs continue to thrive and meet the changing needs of program participants. It has been demonstrated through these programs that the participant-centered approach improves the quality of long term support systems. When people have choices, individualized plans are built on a foundation of participant strengths and respond more effectively to participants' needs. Seventeen years of experience with COP and the Waivers has shown that listening to the collective participant voice is essential to developing policy and programs.

Strategies for Incorporating the Participant Voice

There are a variety of ways in which the participant voice can become integrated into county policy, processes, and system management. Most of these approaches are simple and can be built into everyday care management activities.

Strategy #1 – Well-defined Approach to Care Management

Developing and implementing a well-defined, participant-centered approach to care management is important to the inclusion of the participant voice. By setting clear expectations and guidelines for care managers, counties support the goals of participants and of the COP and waiver programs as a whole. The leadership of county supervisors, directors, and other lead staff in bringing the participant voice to all aspects of program sets the tone for care managers to continue to support participant-centered assessment and care planning.

Strategy #2 – Care Planning

Care managers incorporate the participant voice by working to understand participants' lives and goals and developing care plans based on this knowledge. This can be accomplished by:

- Involving participants as key players in care planning
- Discussing participants' and care managers' roles and how they best support participants' goals
- Developing an understanding of participants' priorities, strengths, and skills
- Determining available natural supports and building participant care plan around them
- Partnering to explore less traditional community resources when meeting a need
- Providing information and the opportunity to experience different services to support informed decision-making

Strategy #3 – Listening to Participants

There are many ways to directly access participant input and feedback to impact county policy, processes, and service delivery. Knowing what is important to participants in long term care, understanding the service issues they deal with, and soliciting their ideas for improvement will ultimately enhance the quality of service delivery. This can be accomplished through:

- **Everyday Interactions**

The simplest method of obtaining participant voice comes through everyday interactions. Participants inform members of their family, county staff, healthcare providers, guardians, and service providers about what is and is not working for them, and they share ideas or provide feedback. By actively checking in with participants and their supports, care managers understand evolving needs and develop a broad understanding of how county policy impact participants' lives. In turn, supervisors and directors need to be responsive to care managers' input about the participant experience.

- **Formal Surveys: Moving Beyond Satisfaction and Targeting Specific Outcomes**

Participant surveys that go beyond "satisfaction" to assess participants' quality of life can be an effective method of obtaining input and feedback. Utilizing an internal, outcome-based survey could support county agencies to determine what areas of life are most important to participants. By gathering information about the impact of services on people's lives, rather than the services themselves, an outcome-based survey could identify areas in which the county systems may be enhancing participants' quality of life or target areas that might benefit from improvement.

- **Participant Involvement**

Involvement on county boards and in participant focus groups or special projects encourages participants to actively impact program planning and decision making. In addition, the development of peer groups could provide support and guidance to participants, as well as the opportunity to share their experiences and concerns with other program participants. In this way, participants could share strategies for problem solving, network with other participants, and discover new resources.

Strategy #4 – Sharing What You Learn

These changes or improvements within county systems are especially effective when the agencies or persons implementing them support and promote the philosophy behind it. The philosophy and approach of proactive, participant-centered programs should be shared with service vendors, contracted agencies, local pharmacies, and health care providers.

Similarly, letting participants know the value of their input is an important step toward encouraging their involvement. When participants are aware that counties value their suggestions and utilize their feedback to make system-wide improvements, they recognize that their experience can impact the quality of program participants' lives.

How Are Counties Incorporating the Participant Voice?

Richland County

When Richland County began its involvement with Family Care, it embraced the participant-oriented approach. To understand how to acquire and utilize input from participants, the county developed an advisory group consisting of participants, family members, guardians, and aging network staff. This group participated in a four-hour training on the concepts of Long Term Care and Family Care. They also attended a one-day planning session.

As a result of this preparation, the advisory group worked together and developed several approaches to obtaining participant input. They suggested that Richland County consider approaching small community groups to discuss long term care issues and the participant voice. The group also encouraged the county to conduct a survey requesting input from current participants and their family members or guardians. For those people not able to complete the survey, the county organized a group of active elders in the community to assist participants with their responses. Like the advisory group, this group was trained to administer the survey and capture participant input.

Richland County is also preparing for Family Care by coordinating work groups consisting of acute primary care providers from the community, which include physician assistants and hospital social workers. The goal of these work groups is to meet with participants to better coordinate services for them by connecting and improving communication between people involved in participants' care plans. These work groups meet with other professionals in their fields and discuss ways of developing these connections for participants.

Other work groups being developed include care managers and service providers whose objective will be to talk to participants about issues such as better coordinating and improving the quality of their services.

Richland County has also developed a position for a Member Relations Coordinator. This person's responsibilities include being an internal advocate for participants, spending time with participants to relay information, encouraging participant involvement in meetings and joint committees, and helping participants understand the long term care system.

Marathon County

One of Marathon County's residents and CIP II participants illustrates the impact one person can have on county and statewide long term care programs. This participant is an outstanding self-advocate and a strong proponent of participant involvement. Not only does he serve as the chair for the North Country Independent Living Center, but he is also the governor-appointed vice-chair for the State Independent Living Council (SILC), a member of the Wisconsin Rehab Council (also appointed by the governor), and a member of the Board of Disability Rights Coalition, which is affiliated with Grass Roots Advocacy.

The participant's leadership in these organizations and his skills as an adept advocate encourage other participants to become active in their county programs. His involvement in organizations like SILC and the Disability Rights Coalition has given him the opportunity to speak to people who have disabilities, reminding them that they can lead independent lives. He strongly encourages participants to express their desires and preferences, stating, "Consumers know their own needs better than anyone else; in turn, care managers must *listen* to the consumers."

By speaking to groups such as the Lion's Club and the Muscular Dystrophy Association, as well to camps for people with disabilities and public school children, this participant teaches others how to advocate for themselves and understand their rights. As a CIP II participant, he applies his own message with great success both for him and for Marathon County. In one instance, the participant saved the county \$1,000 for a home modification by finding a less expensive builder. He supports and inspires other participants to use their strengths and skills to self-advocate and to take charge of their own lives. He is a great example of how participants can make a difference in their own lives and in the lives of participants statewide.

Green County

Green County captures the participant voice in a variety of ways. The county requires that each of their Long Term Support Committee members visit one or two participants every year. During these conversations, participants are asked to talk about their lives, their experience on the program, the aspects of the program that are working well, and those that have not met their needs. The county uses this information to learn how their system is supporting participants' quality of life.

Green County also invites participants to the LTS committee meetings. On average, three or four participants attend each session. The committee encourages them to discuss how they have benefited from being on the waiver program and to raise any issues or concerns they have. This dialogue strengthens the connection between participants and the LTS committee and encourages ongoing discussions and input from participants.

To support their efforts to capture the participant voice, Green County also conducts a satisfaction survey. In previous years, this survey consisted of questions related to specific elements of Green County's waiver program, such as care management or supportive home care. This year the county updated its survey to focus on "the whole assessment process." Participants were encouraged to answer the questions candidly and to identify any issues that were of concern. Participants were not required to include

their names, but those who reported dissatisfaction with the program were encouraged to do so, so that the county could address their concerns immediately. Linda Boll, supervisor, indicated that 80% of the surveys distributed were returned, and only a few responses contained negative comments. These concerns were addressed immediately.

Finally, Green County has a contractual agreement with its supportive home care providers to conduct satisfaction surveys every year. The results of these surveys are sent to Green County for evaluation. Overall, results from the supportive home care surveys have been positive.

Conclusion

This is only a sampling of county approaches to capturing the participant voice. Each county emphasizes, in its own way, the importance of listening and learning from participants.

If your agency is doing something innovative to incorporate the participant voice, please call your county COP-Waiver Quality Assurance contact at TMG at (608) 255-6441. We look forward to hearing from you and sharing your experiences with other counties.